

Families and mental health workers: the need for partnership

MARGARET LEGGATT

World Schizophrenia
Fellowship, 238
Davenport Road, Box
118, Toronto, Ontario,
M5R 1J6, Canada

In Western countries, the movement from treatment in large mental hospitals to treatment in community mental health facilities has resulted in a heavy burden of care for the families of people with mental illness (1). The nature of this caregiving role is often not understood by professional mental health workers. Blaming families for causing these illnesses has not completely disappeared, although it is decreasing as evidence mounts for a neurobiological explanation of mental illness.

Families are frequently excluded from treatment and care plans. Reasons for this include the belief that the individual has the right to a confidential relationship with his doctor. Mental health professionals are trained to maintain confidentiality. This can assume precedence over other treatment and care issues that may be of greater benefit to the patient (2). Secondly, mental health professionals are not skilled in working with families. Some recent programs now train mental health workers to provide families with the skills needed to be active, positive carers rather than passive victims to the difficult situations created by a relative's illness (3).

In Eastern societies, the relationship between families and mental health professionals is different. Families have never been excluded from the treatment process, and are the mainstay of care for their relatives with mental illness. Confidentiality is not a problem, although stigma is even greater than it is in the West. Nevertheless, the intrinsic and tremendous potential of families to facilitate recovery in their ill relative has generally not been recognized. Families receive information about the need to continue medication (in fact, medication is often entirely supervised by families and the patient is only a passive participant). In developing countries, caregivers have a major role to play in the resocialisation, vocational and social skills training of the patient, not only because of close family ties that exist in these traditional societies, but also because developing countries lack rehabilitation professionals to deliver these services. Carer burden is exacerbated by issues of poverty and illiteracy (4).

Regardless of whether the country is in the developed or developing world, there are too few instances where families receive the information,

education, training and emotional support that they need in order to facilitate their loved one's recovery.

FAMILIES HELPING FAMILIES

Failure of mental health systems to involve family carers has resulted in the growth of family self-help organizations. Some of these organizations have developed their own often highly sophisticated information, education and support programs, such as 'Understanding and coping with schizophrenia: 14 principles for the relatives' (5) and the 'Family-to-family education program' (6). Family members who develop these programs use their personal 'lived experiences' of day-to-day coping with mental illness in a close relative as the basis for teaching other families how to cope. They claim that their personal experience gives them a deeper understanding of what does or does not work; an understanding that inexperienced professional workers often do not appreciate.

These programs have not been subjected to rigorous evaluation, nor are they likely to be mentioned in professional journals. Self-help organizations rarely have the money or the expertise to carry out the necessary steps to have their work recognized in evidence-based research. Nevertheless, thousands of family carers will attest to their value, claiming that the real difference in their lives came from attendance at these 'peer support' educational courses (7).

Part of the family carers' subjective burden relates to the failure of mental health professionals to listen to and include family members in their mentally ill relative's treatment and care plan. Perhaps this is not surprising as the professional mental health workforce has little real training in psycho-education as a total package of care. Goldstein (8) states that he has 'observed a resistance to applying these techniques ...many practitioners have never worked with families and understandably find the prospect quite intimidating.'

Where they exist, the development of family initiated and implemented programs presently provide for many of the needs of family carers, but there is concern that they may become a substitute for, and therefore prevent or delay the development of comprehensive psycho-

education, where a strong emphasis is put upon the development of a collaborative relationship between clinicians, family carers and patients.

The strongest reasons for the implementation of programs that emphasise collaborative partnerships are summarized in the following statement: "Since 1980, twenty-two controlled studies of long-term cognitive-behavioural family interventions integrated with optimal drug and case management have shown substantial additional benefits for people with schizophrenic disorders. These include 14 random-controlled comparisons carried out with sound scientific methods that document the significant clinical, social and economic advantages of these new approaches that include patients, relatives and close friends in the continuing care program.... All recent authoritative reviews of this body of research have reached a consistent conclusion that further delays in implementing these methods in clinical practice can no longer be justified, either on the grounds of insufficient scientific evidence for their effectiveness, or on account of problems with securing additional manpower resources for implementation" (9).

Although these trials have been carried out predominantly in the West, there are notable inclusions from trials in China.

PRINCIPLES FOR WORKING WITH FAMILIES

The World Fellowship for Schizophrenia and Allied Disorders - an international organization of national family support organizations - developed principles for working with families as the first step in its 'Families as partners in care' project (10). These principles are particularly relevant for countries where there is a mental health workforce able to be trained in 'family interventions'. Variations of these principles are presently being formulated for countries where numbers of mental health professionals and services are minimal. Nevertheless, many of these principles are relevant regardless of differing social, economic and cultural conditions.

The following principles, drawn from positive evidence found in research, state the need to:

- *Coordinate all elements of treatment and rehabilitation to ensure that everyone is working towards the same goals in a collaborative, supportive relationship.* Working together ensures that the goals for treatment and care are understood and agreed by the treatment team which includes the family. This will overcome the isolation that is experienced by both professionals and families.
- *Pay attention to the social, as well as the clinical needs of the patient.* It is insufficient to focus exclusively on medication management. Needs for appropriate accommodation, employment or alternative occupation, economic support, recreation and a supportive social network must be taken into account.
- *Provide optimum medication management.* Clinicians should be alert to signs of overmedication and to the unpleasant and disabling side effects of antipsychotics. There should be regular reviews of the medication with the patient and family. Education about

medications plus regular assessment, particularly in relation to side effects, will encourage compliance.

- *Listen to families and treat them as equal partners.* Relatives have gained a great deal of experience and have much to teach professional caregivers. Their expertise should be acknowledged and valued. Clinicians should consult with family throughout the treatment and care program, to improve effectiveness, understanding and empathy. Speaking to families in their homes may help in initiating family contact.

- *Explore family members expectations,* concerning: a) the treatment program (each family member may have different expectations; because these may be unrealistic it is important to explain what the team hopes to achieve); b) the patient (after an episode of illness, particularly at the beginning, family members may expect the person to return rapidly to his/her previous level of functioning; the family will need to adjust their expectations and form new goals; throughout the treatment process, family and patient expectations have to be regularly evaluated).

- *Assess the family's strengths and difficulties.* It is too easy to focus on the family's problems and ignore their strengths. Simply staying together constitutes a strength. A major strength is their intimate knowledge of the patient and what they have learned through a process of trial and error. Caring for someone with a mental illness exacts an emotional toll. Anxiety and depression should not be neglected. These symptoms reduce their capacity to support the patient.

- *Help resolve family conflict by providing sensitive response to emotional stress.* Anger, anxiety and guilt expressed by family members should be dealt with in a sensitive way. Anger can usually be reframed as showing concern. Expressions of warmth are encouraged. Recreational activities should be promoted that are likely to lead to family members enjoying things together. When conflicts stemming from antagonistic relationships arise, clinicians need to listen to the differing viewpoints impartially and seek resolution through compromise.

- *Address feelings of loss.* Family members experience loss of hopes and expectations for their sick relative. They also feel that the person they know has been changed by the illness. Their grief needs to be acknowledged. They need help in coming to terms with both these kinds of loss.

- *Provide relevant information for patient and family at appropriate times.* An introductory education program is an effective way of engaging families, but needs to be followed by continuing education throughout the period of treatment and care. Clinicians and families need to appreciate each patient's individual signs of relapse in order to bring about an early treatment intervention. Each family has its own concerns which need to be addressed. In addition, clinicians should recommend that the family attend a support group.

- *Provide an explicit response plan for crises.* The family should have access to the treatment team when they know that their relative is in danger of relapse. A provisional plan, which includes relevant telephone numbers of key contacts and services, should be in place.

- *Encourage clear communication among family members.* In some

families, members find it difficult to communicate with each other. They have stopped listening. It is common for the person with mental illness to be left out of discussions. Clinicians need to suggest simple ground rules for clear communication, and support the family in their efforts to observe them.

- *Provide training for the family in structured problem-solving techniques.* This cognitive-behavioural approach is of great value in helping families to tackle the main problems they face in caring for a person with mental illness. It is sensible to guide the family towards applying the techniques to a simple problem first, so that they are likely to achieve success.

- *Encourage the family to expand their social support networks.* Families tend to withdraw from their natural support networks through burden, shame and embarrassment. Initially they benefit from social interaction through relatives' support groups, or multi-family problem solving groups. It is important that the caring role does not absorb all their life and that a balance be maintained. Patients may be helped to increase their social activity by social skills training, often with the assistance of siblings and friends.

- *Be flexible in meeting the needs of the family.* Clinicians may decide to work with a single family or groups of families. Family members and/or the patient may need to be seen separately. The patient may need to discuss some concerns privately when they do not concern the family.

- *Provide the family with easy access to a professional in case of need if work with the family ceases.* It is essential to leave the family with a phone number and a named person who will deal with any future enquiries. Sometimes a telephone discussion will suffice; at other times additional sessions may be required to help family to cope with a crisis or a change in their circumstances.

Some family carers who gain confidence in their caregiving role should be used as:

- *Educators and trainers of mental health professionals.* Work with families can take place through a 'reflective' learning process between family care and professionals at undergraduate and postgraduate levels of training as well as in-service workplace training.

- *Advisors at all levels of policy development in mental health services.* Family and consumer perspectives must inform mental health policies through advocacy groups alerting governments to mental health issues.

- *Advocates for community acceptance of mental illness.* Carer organizations have an important role in mental health advocacy, particularly through community awareness campaigns aimed at reducing the stigma associated with mental illness.

- *Developers of a wide range of community support services.* Family organisations in both developed and developing countries have raised funds for, and then run 'drop-in' centers, rehabilitation programs, accommodation facilities and respite care services (11).

References

1. Johnson D. Current issues in family research: can the burden of mental illness be relieved? In: Lefley HP, Wasow M (eds). *Helping families cope with mental illness*. Chur: Harwood Academic Publishers, 1994:309-28.
2. Furlong M, Leggatt M. Reconciling the patient's right to confidentiality and the family's need to know. *Aust N Z J Psychiatry* 1996;30:614-23.
3. National Schizophrenia Fellowship/Sainsbury Center for Mental Health. *Learning to cope together: implementation and evaluation of the National Schizophrenia Fellowship/ Sainsbury Centre for Mental Health carers' education and support project*. 1998.
4. Shankar R, Menon MS. Interventions with families of people with schizophrenia: the issues facing a community rehabilitation center in India. *Psychosoc Rehabil J* 1991;15:85-90.
5. Alexander K. *Understanding and coping with schizophrenia: 14 principles for the relatives*. Melbourne: Schwartz and Wilkinson, 1991.
6. Burland J. Family-to-family: a trauma and recovery model of family education. *New Directions for Mental Health Services* 1998;77:33-41.
7. SANE. *Blueprint guide to carer education and training*. 1999.
8. Goldstein MJ. Psychoeducation and relapse prevention. *Int Clin Psychopharmacol* 1995;9(Suppl 5):59-69.
9. World Schizophrenia Fellowship. *Families as partners in care*. 1998.
10. World Fellowship for Schizophrenia and Allied Disorders. *Principles for working with families*. 2001.
11. Leggatt M. Carers and carer organizations. In: Thornicroft G, Szmukler G (eds). *Textbook of community psychiatry*. Oxford: Oxford University Press, 2001:475-86.